

Letter to the Editor: Re: SIOP Working Committee on Psychosocial Issues— Guidelines for Care of Long-Term Survivors

I wish to present a diametrically opposed view to the one SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Care of Long-term Survivors, published in *Medical and Pediatric Oncology*, 27:1–2, 1996.

My opposition to the views expressed by this working committee is based on two rather obvious facts. The first, is that healthy individuals do not need to attend health professionals. The second, is that in formulating the views of the SIOP working committee, I could see no evidence that the “consumers” had been consulted. As a result of these omissions, the recommendations of the working committee perpetuate the concept that children who are cured of childhood cancer are unhealthy adults.

It is true that unfortunately there are children whose treatment for childhood cancer has either physically or emotionally disfigured them for life. Such patients do require the assistance of multiple health professionals, preferably in their community and away from the center in which they were treated for childhood cancer. They should be given the opportunity, should they so wish, to return to treating oncologists and to discuss issues which have arisen from re-integration into their social circle, but they should not be requested to attend regularly for follow-up clinics in the same institution where they were treated for their cancer.

The majority of children treated for cancer in recent decades do not have long-term consequences of treatment which require their “medicalisation” for life. Shouldn't it be better to give them the option of being informed of the likely long-term consequences and to credit their intelligence to seek assistance should they occur.

This approach has the advantage of returning the responsibility for one's health and one's life to the patient, something which oncologists, by necessity, remove from patients and, in my experience, are very loath to return it to them. The responsibility for one's own welfare is an essential part of achieving maturity and unfortunately the programme proposed by the SIOP working committee, if fully implemented, would achieve the exact opposite.

I suspect that I am not the only paediatric oncologist

who holds this point of view. Perhaps the publication of this letter may stimulate debate on the fundamental issues raised by the SIOP working committee.

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Reply

We are in complete agreement with Prof. Ekert's view that we should not treat survivors of childhood cancer as unhealthy adults. In several places in our published guidelines, we acknowledge that the vast majority of survivors will be healthy. We speak of linkage with community physicians and the need for these physicians to be fully informed of their patients' past cancer history in order that they might better care for each patient's needs.

The intent of our paper is to insure that those few cancer survivors with significant side effects from the cancer treatment are adequately cared for, both for the side effects and for any additional health problems resulting from the side effects.

One of the critiques in Prof. Ekert's letter was that we wish to hold on to patients who prefer to go elsewhere. The truth is that the patients return to us, because they feel they will receive proper medical advice and support. Our intent is to systematize what some centers do anyway, to insure that no one who has a medical need, resulting from the original cancer fails to receive proper medical care. Our proposal is for the cancer center to serve as a referral service, to offer, not require, check-ups for people who wish them. Our concern is that the patient receive complete medical and psychosocial follow-up care.

We regret that Prof. Ekert read our guidelines in a negative way. Hopefully, this letter of response will help underscore our original intent.

Prof. Giuseppe Masera